

# A role for the sick role

## *Patient preferences regarding information and participation in clinical decision-making*

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### Abstract

**Objective:** To assess whether patient preferences regarding information and participation in decision-making about treatment options are related to patient characteristics and the context of the decision. Other studies have compared decision-making preferences in patients with cancer and healthy subjects, or in different contexts among patients in the same group. This study combined these designs.

**Design:** Questionnaire completed by the subjects.

**Setting:** Outpatient clinic of a university hospital.

**Participants:** A consecutive sample of 55 patients with cancer treated at a radiotherapy clinic, 53 persons accompanying them, a consecutive sample of 53 patients visiting a surgical outpatient clinic for a nonmalignant condition and 36 persons accompanying them.

**Main measures:** Preferences regarding information and participation in decision-making in general and with respect to 4 vignettes that described different diseases of varying seriousness, varying treatment options and side effects.

**Results:** Older patients and men were more likely to let the physician make decisions regarding their treatment. Patients, as compared with nonpatients (their companions), were more likely to prefer a passive role regarding treatment decisions. No differences were seen between patients with cancer and patients with nonmalignant conditions. Also, no effect was observed in relation to the decision-making situations described in the vignettes. Of the patients who preferred more information, a substantial proportion still preferred a passive decision-making role.

**Conclusion:** The lack of strong predictors of a preferred decision-making role implies that clinicians need to assess every patient individually to determine what role he or she prefers. The finding that the patients preferred a more passive role than their companions suggests that the "sick role" influences the preference regarding participation more strongly than the type of decision to be made or the presence of a life-threatening disease. This hypothesized shift in preference among subjects who are sick implies that these patients need encouragement to participate.

### Résumé

**Objectif :** Évaluer s'il y a un lien entre les préférences des patients en ce qui concerne l'information et la participation à la prise de décisions sur les traitements possibles, d'une part, et les caractéristiques du patient et le contexte de la décision, de l'autre. Dans le cadre d'autres études, on a comparé les préférences décisionnelles de patients atteints du cancer et celles de sujets en bonne santé, ou dans des contextes différents parmi des patients du même groupe. Cette étude a combiné ces concepts.

**Concept :** Questionnaire auquel ont répondu les sujets.

**Contexte :** Clinique externe d'un hôpital universitaire.

**Participants :** Un échantillon consécutif de 55 patients atteints du cancer traités à une clinique de radiothérapie et de 53 personnes qui les accompagnaient, un échantillon consécutif de 53 patients qui se sont présentés à une clinique externe chirurgicale pour traitement d'une infection non maligne et de 36 personnes qui les accompagnaient.

**Principales mesures :** Préférences relatives à l'information et à la participation à la

### Evidence

### Études



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prise de décisions en général et à 4 vignettes décrivant des maladies différentes de gravité variable, des traitements possibles et des effets indésirables.

**Résultats :** Les patients plus âgés et les hommes étaient plus susceptibles de laisser le médecin prendre les décisions au sujet de leur traitement. Comparativement aux non-patients (personnes qui les accompagnaient), les patients étaient plus susceptibles de préférer un rôle passif au sujet des décisions relatives au traitement. On n'a constaté aucune différence entre les patients atteints d'un cancer et les patients atteints d'une affection non maligne. En outre, on n'a remarqué aucun effet par rapport aux situations décisionnelles décrites dans les vignettes. Parmi les patients qui préféraient avoir plus de renseignements, beaucoup préféraient quand même un rôle décisionnel passif.

**Conclusion :** Le manque de prédicteurs solides d'un rôle décisionnel préféré sous-entend que les cliniciens doivent évaluer chaque patient individuellement pour déterminer le rôle que celui-ci préfère. La constatation selon laquelle les patients préféraient un rôle plus passif que les personnes qui les accompagnaient sous-entend que le «rôle de malade» a plus d'effet sur la préférence relative à la participation qu'en ont le type de décision à prendre ou la présence d'une maladie dangereuse. Ce déplacement hypothétique des préférences chez les sujets malades sous-entend qu'il faut encourager ces patients à participer.

The concept of “shared decision-making” assumes that all patients prefer to receive information on their condition or disease and wish to participate in decision-making. However, this assumed universality does not seem to be the case. For example, younger subjects have consistently been found to have a stronger preference for participation than older subjects.<sup>1-4</sup> Also, some studies have found higher education levels to be associated with a stronger preference for decision-making,<sup>4,6</sup> yet in other studies this association was confounded by age.<sup>2,7</sup> However, the amount of variation in decision-making preference explained by such factors generally does not exceed 15%.<sup>1,7</sup>

Faced with life-threatening diseases, patients seem to prefer a more passive role.<sup>5,8</sup> Differences have been found between patients with cancer and the general public, with patients displaying a stronger wish to leave decisions to the physician.<sup>7</sup> In addition, progression of disease may be associated with a decreased wish for participation.<sup>1</sup>

According to Deber,<sup>9</sup> 2 dimensions of choice have been confused: “problem-solving” (requiring medical expertise) and “decision-making” (involving values and preferences). She asserts that patients who do not appear to want to participate may have simply rejected a role in the problem-solving aspect.

Cassileth and colleagues<sup>2</sup> note that preferences regarding information and participation represent components of a single attitude, given their high correlation. However, in later studies this correlation has not always been confirmed.<sup>5,6,10</sup>

The goal of studies such as these is to help clinicians provide their patients with the type and amount of information that match their needs. Shared decision-making may lead to increased satisfaction with the decision and

consequently to better compliance and better health outcomes.<sup>11-13</sup> Furthermore, it may enhance patients' self-esteem and increase clinicians' awareness of patients' expectations and preferences.<sup>4</sup>

The purpose of our study was to assess whether preferences regarding information and participation were related to patient characteristics and the context of the decision. In other studies, patients with cancer and healthy subjects have been compared<sup>7</sup> or different contexts have been studied in 1 subject group.<sup>1,5</sup> We combined these designs by assessing the responses of patients with cancer, patients with nonmalignant conditions and healthy control subjects in different contexts. We wished to investigate whether there was a difference in decision-making preference among these groups and in their responses to situations involving life-threatening disease (cancer) and to those involving non-life-threatening disease.

## Methods

### Subjects and procedures

Four groups of subjects participated: patients with cancer receiving treatment at a radiotherapy clinic (57 were approached, 55 participated); the persons accompanying these patients (55 were approached, 53 participated); patients attending an outpatient clinic for follow-up after surgery for a nonmalignant condition (60 were approached, 53 participated); and the persons accompanying these patients (45 were approached, 36 participated). The patients formed a consecutive sample seen at Leiden University Medical Center, Leiden, The Netherlands. Subjects who had a diagnosis of 1 of the 4 diseases described in the vignette section of the questionnaire (Appendix 1) were not eligible to



participate. The study was approved by the ethics review board of the Leiden University Medical Center.

The questionnaires were handed out by a research assistant and were completed by the subjects. The subjects were assured of the anonymity of the questionnaire, and the patients were told they could refuse to participate without prejudice to their medical care.

The questionnaire consisted of 3 sections. The first pertained to the subjects' sociodemographic and disease characteristics (age, sex, marital status, education, disease for which the patient was undergoing treatment, and any experience with disease and treatment [companions only]). The second section focused on patient attitudes toward information and participation in general (Table 1, translated into Dutch, from Sutherland and associates<sup>10</sup> and Llewellyn-Thomas and collaborators<sup>14</sup>). The third section consisted of 4 vignettes about treatment options for various diseases, for which preferences regarding information and participation were elicited. The vignettes varied with respect to seriousness of disease (benign v. malignant) and side effects of treatment (minor v. major). The 4 diseases in the vignettes were tinea of the foot, asymptomatic gallstones, laryngeal cancer and skin cancer. For each, the subjects were asked whether they felt the information given was sufficient, and what role they would want to play in the decision-making regarding treatment (Table 1, question 2).

### Data analysis

The answers to the questions on preferences regarding information and participation were tabulated according to the patient characteristics, and associations were tested using the  $\chi^2$  test. To assess the effect of more than 1 independent variable simultaneously, analysis of variance (ANOVA) was used for the ranked answers to the question regarding the decision-making role (Table 1, question 2).

To assess whether the preferred decision-making roles were different among the 4 vignettes, Friedman nonparametric ANOVA was used, treating the decision-role question as an ordinal variable (5 levels). Such nonparametric analyses were also carried out for the association with age, sex and education. To assess these effects simultaneously, repeated measures ANOVA was carried out on the ranked decision-role data, with each vignette as a within-subject factor.

In the analysis of the association between preferred decision-making role and patient characteristics we also combined the decision-making roles into "active," "collaborative" and "passive" in the manner of Degner and Sloan.<sup>7</sup> We defined patients as active if they preferred to make the decisions themselves (last 2 of the 5 categories), as collaborative if they preferred to make the decisions with the physician on an equal basis, and as passive if they preferred the physician to make the decision (first 2 categories).

## Results

In Table 2 the characteristics of the subjects in the 4 groups are given. Of the companions, 21 (14 of the companions of patients with cancer and 7 of the companions of patients who had undergone surgery) indicated that they were under medical treatment or care, so data about them were not used. This left 39 companions of patients with cancer and 29 companions of patients who had undergone surgery.

Of the patients with cancer, 12 had lung cancer, 10 breast cancer, 10 urogenital cancer, 6 colorectal cancer, 5 lymphoma, 3 head and neck cancer, and 9 other types of cancer.

### Preferences for information

Of all the subjects, 82% stated that they would always want to be informed about all benefits and side effects of a medical treatment; 18% indicated that they would want this information only in some cases. No differences were seen among the 4 groups (patients with cancer, patients who had undergone surgery and the 2 groups of companions) or between the sexes. Trends with respect to age and education were evident, although not significant. Of those 65 years and older, 24% stated that they would want to be fully informed only in some cases, whereas the proportion of those in the younger age groups who chose this answer ranged from 14% to 18%. Among those with the highest education level (university/professional), 93% stated that they would always want to be informed, whereas 80% of those in the lower education categories stated this.

Most of the subjects considered the information in the

**Table 1: Questions on subjects' preference regarding information and participation in medical decisions**

1. In general, would you always want to be fully informed about all benefits and harms of a medical treatment?
  - ☐ Yes, always
  - ☐ In some cases
  - ☐ No, never
2. After being informed about treatment options, some people prefer to leave decisions about their treatment up to their physician, whereas others prefer to make the decisions themselves. Please check the statement that best describes your preference in general:
  - ☐ The physician should make the decisions using all that is known about the different treatments
  - ☐ The physician should make the decisions, but strongly consider my opinion
  - ☐ The physician and I should make the decisions together on an equal basis
  - ☐ I should make the decisions, but strongly consider the doctor's opinion
  - ☐ I should make the decisions using all I know or learn about the treatments

vignettes to be sufficient. No significant differences were seen among the vignettes, but there was a trend toward a greater need for information for the more serious diseases presented in the vignettes. For tinea 12% considered the information insufficient, for gallstones this figure was 15%, and for skin and laryngeal cancer it was 19% and 22% respectively.

The subjects' evaluation of the amount of information in the vignettes was strongly related to both age and education. For all but the tinea vignette, patients who judged the information insufficient were significantly younger, by about 8 to 12 years, than those who judged the information sufficient ( $p \leq 0.005$ ). For the tinea vignette the age difference was only 6 years ( $p = 0.16$ ). Subjects with a higher education level were more likely to rate the information in all the vignettes as insufficient. This association with education remained when age was controlled for in a repeated measures ANOVA on the ranked information questions (for age  $p = 0.002$ ; for education  $p \leq 0.001$ ). No significant effect related to the different vignettes was seen.

## **Preferences regarding a decision-making role**

Table 3 shows the responses to the question about preference regarding a general decision-making role. For all but the companions of the patients who had undergone surgery the second statement ("the physician should make the decisions, but strongly consider my opinion") was chosen most often; the companions of the patients who had had surgery selected collaborative decision-making most often (45%). There was a trend toward the companions of both groups preferring a more active role than the patients, but it was not a significant difference.

The association between role preference (combined into active, collaborative and passive categories) and group in response to the vignettes is shown in Table 4. For each of the 4 vignettes, a larger proportion of the companions than of the patients chose an active decision-making role. For the individual vignettes the difference between patients and companions was statistically significant only for the gallstone vignette ( $p = 0.05$ ), but when

**Table 2: Characteristics of the subjects in the study**

Characteristic	Subject group			
	Patients with cancer <i>n</i> = 55	Companions of patients with cancer <i>n</i> = 39	Patients who had undergone surgery <i>n</i> = 53	Companions of patients who had undergone surgery <i>n</i> = 29
Mean age, yr (and standard deviation)	56 (16)	53 (14)	43 (19)	46 (16)
Sex, % male	57	39	51	38
Years or level of education, % of subjects				
< 8 yr	22	10	14	7
9–12 yr	35	44	33	41
12–14 yr	25	36	31	41
University/professional	18	10	22	11

**Table 3: Subjects' preferred decision-making role in the general situation**

Role	Subject group; no. (and %) of subjects			
	Patients with cancer <i>n</i> = 52	Companions of patients with cancer <i>n</i> = 37	Patients who had undergone surgery <i>n</i> = 48	Companions of patients who had undergone surgery <i>n</i> = 28
The physician should make the decisions using all that is known about the different treatments	10 (19)	2 (5)	7 (15)	3 (11)
The physician should make the decisions, but strongly consider my opinion	22 (42)	15 (41)	18 (38)	7 (25)
The physician and I should make the decisions together on an equal basis	13 (25)	9 (24)	12 (25)	12 (43)
I should make the decisions, but strongly consider the doctor's opinion	7 (13)	11 (30)	10 (21)	5 (18)
I should make the decisions using all I know or learn about the treatments	0	0	1 (2)	1 (4)



the difference between patients and companions was tested using the information from all 4 vignettes the difference was significant ( $p = 0.03$ ). No significant difference in decision-making preference was seen between the 2 patient groups or between the 2 companion groups.

No significant effects related to the various vignettes were seen, either overall or by subject group.

Age was strongly associated with choice of decision-making role in the general question, with older subjects preferring a more passive role and younger patients a more active role (Table 5;  $p = 0.006$ ). Table 5 also shows the association between role preference and age for the 4 vignettes. There was an association for the 2 vignettes that did not involve a diagnosis of cancer, with older patients preferring a more passive role; however, the association was not as clear for the vignettes involving cancer, as the younger patients preferred a less active role in these situations.

In response to the question about decision-making regarding treatment in general, more women (27%) than men (15%) indicated a preference for an active role. The proportions of subjects who chose collaborative and passive roles were 34% and 40%, respectively, for women, and 22% and 63%, respectively, for men ( $p = 0.01$ ). This association was also seen for the vignettes, but was not

significant for laryngeal cancer ( $p = 0.16$ ) because the proportions of male and female patients choosing a collaborative role were more similar.

Since the mean age and sex distribution for the 4 groups differed (Table 2) and the women in the study were younger than the men (mean 48 v. 52 years), we tested the effects of group and sex in an ANOVA on the ranked general decision-role question (5 categories) with age as a covariate. In this analysis, the effects of sex, group (patients v. companions) and age all remained. A similar test was carried out for the 4 vignettes using repeated measures ANOVA. The same effects held, and no significant effect of vignette was seen.

No association between education level and decision-role preference was seen.

Preferences regarding participation and information were not clearly associated. For the gallstones and skin cancer vignettes, the patients who preferred an active role were more likely to indicate that the information was insufficient ( $p = 0.16$  and  $0.20$ , respectively). For the laryngeal cancer vignette the same proportion of subjects in all 3 decision-making preference groups rated the information as insufficient. Among those who felt the information in the vignettes to be insufficient, a substantial proportion, ranging

**Table 4: Association between subjects' preferred decision-making role and group (patients v. companions) for the 4 vignettes\***

Vignette; role	Subject group; no. (and %) of subjects†			
	Patients with cancer	Patients who had undergone surgery	Companions of patients with cancer	Companions of patients who had undergone surgery
<b>Tinea of the foot</b>				
Passive	27 (52)	20 (41)	13 (34)	11 (40)
Collaborative	16 (31)	17 (34)	12 (32)	8 (29)
Active	9 (17)	12 (25)	13 (34)	9 (32)
<b>Gallstones</b>				
Passive	26 (48)	18 (36)	12 (32)	7 (26)
Collaborative	20 (37)	19 (38)	12 (32)	10 (37)
Active	8 (15)	13 (26)	14 (37)	10 (37)
<b>Laryngeal cancer</b>				
Passive	26 (50)	20 (44)	11 (30)	9 (35)
Collaborative	17 (33)	17 (37)	14 (38)	11 (42)
Active	9 (17)	9 (20)	12 (32)	6 (23)
<b>Skin cancer</b>				
Passive	26 (51)	20 (42)	15 (40)	10 (37)
Collaborative	18 (35)	21 (44)	13 (34)	10 (37)
Active	7 (14)	7 (15)	10 (26)	7 (26)

\* $p = 0.03$  for overall association between decision-making role and group, combining the information from the 4 vignettes in a repeated measures analysis of variance (using the 5 response categories from Table 1).

†The number of responses, and hence the denominator, varies among vignettes.





from 6% for the tinea vignette to 23% for the laryngeal cancer vignette, preferred a passive decision-making role.

## Discussion

We found a striking difference between the patients and their companions with respect to decision-making preferences, and no significant differences between the patients with cancer and the patients who had undergone surgery. This finding suggests that it is more the fact of being a patient per se than having a serious diagnosis such as cancer that makes subjects prefer a more passive role in decision-making. The finding of an effect related to being a patient instead of one related to the different vignettes suggests that the patient role exerts a stronger effect than the type of decision on the wish to participate in decision-making. It has been suggested that, for more life-threatening diseases, patients may be less willing to assume responsibility for the outcome.<sup>7,8</sup> However, our design, which compared patients with cancer, patients with non-malignant conditions and healthy subjects, and which used vignettes involving cancer and less serious diseases,

points to another explanation. It appears that the mere fact of being a patient leads to a shift in preference away from participation. This points to sick-role theory, which suggests that cultural expectations of responsibility change during illness and that sick individuals are not held responsible for normal role behaviour.<sup>15,16</sup> The implication of this finding is that people in general want to participate in health care decision-making and are less enthusiastic about being involved only when they are sick. From this one may conclude that sick patients need encouragement to participate, or that clinicians need to find appropriate proxies for their patients and involve them in the decision-making process.

A major limitation of our study is that we did not study actual behaviour but relied on responses to vignettes. Most studies of the value of written case simulations pertain to physicians' behaviour.<sup>17</sup> Very little is known about the use of vignettes in patients. One may object that the absence of an effect of the vignettes could be due to measurement error in the vignettes. However, this would not explain the differences found between the patients and the companions but not between the patients with cancer and

**Table 5: Association between subjects' preferred decision-making role and age for the general situation and the 4 vignettes**

Vignette; role	Age group, yr; no. (and %) of subjects*				p value
	< 35	36–50	51–65	≥ 66	
<b>General situation</b>					0.009
Passive	16 (43)	25 (49)	14 (39)	29 (71)	
Collaborative	7 (19)	17 (33)	15 (42)	7 (17)	
Active	14 (38)	9 (18)	7 (19)	5 (12)	
<b>Tinea of the foot</b>					0.001
Passive	12 (31)	17 (33)	13 (36)	29 (73)	
Collaborative	12 (31)	21 (40)	14 (39)	6 (15)	
Active	15 (39)	14 (27)	9 (25)	5 (13)	
<b>Gallstones</b>					0.06
Passive	13 (31)	15 (29)	13 (35)	22 (54)	
Collaborative	11 (28)	20 (39)	17 (46)	13 (32)	
Active	15 (39)	17 (33)	7 (19)	6 (15)	
<b>Laryngeal cancer</b>					0.22
Passive	12 (33)	21 (40)	13 (37)	20 (53)	
Collaborative	11 (31)	21 (40)	13 (37)	14 (37)	
Active	13 (36)	10 (19)	9 (26)	4 (11)	
<b>Skin cancer</b>					0.32
Passive	12 (33)	22 (42)	16 (43)	21 (54)	
Collaborative	13 (36)	20 (39)	14 (38)	15 (39)	
Active	11 (31)	10 (19)	7 (19)	3 (8)	

\*The number of responses, and hence the denominator, varies among vignettes.



those with nonmalignant conditions, which still points in the direction of the patient role.

As expected, younger subjects preferred a more active role in decision-making and required more information. The time between the first role-preference studies and ours has not been long enough to establish whether this is an effect of age per se or of generation.

The finding that women preferred a more active role than men is in line with the findings of Degner and Sloan<sup>7</sup> and Blanchard and associates.<sup>3</sup> Kaplan and collaborators<sup>18</sup> found that men also had the fewest participatory visits. Blanchard and associates<sup>3</sup> hypothesized that this finding may be due to the women's negotiating with health care professionals on behalf of their husbands (since almost all of the older men in their study were married). Most of the men in our study were married as well, and we found that there was a trend toward a more passive role among married women. Thus, the lack of a partner may induce patients to take on a more independent role in the patient-physician relationship.

Among those who felt that the information in the vignettes was insufficient, a substantial proportion preferred a passive role. Thus, a preference for information does not necessarily imply a wish for decision-making.<sup>5,10</sup>

The variation in the wish to participate in decision-making can be explained only to a limited extent by the characteristics of the subjects. Less structured questionnaires or even qualitative research methods are needed to find out what determines this variation. Until more is known about patients' motivations regarding decision-making preferences, clinicians should assess every patient individually regarding the extent to which he or she wishes to be involved. This is the art of patient-centred medicine: determining the appropriate amount of information and participation from the individual patient's perspective.<sup>19</sup>

## References

- Catalan J, Brener N, Andrews H, Day A, Cullum S, Hooker M, et al. Whose health is it? Views about decision-making and information-seeking from people with HIV infection and their professional carers. *AIDS Care* 1994;6:349-56.
- Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med* 1980;92:832-6.
- Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med* 1988;27:1139-45.
- Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *JAMA* 1984;252:2990-4.
- Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 1989;4:23-30.
- Hack TF, Degner LE, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Soc Sci Med* 1994;39:279-89.
- Degner LE, Sloan JA. Decision making during serious illness: What role do patients really want to play? *J Clin Epidemiol* 1992;45:941-50.
- Richards MA, Ramirez AJ, Degner LFD, Fallowfield LJ, Maher EJ, Neuberg J. Offering choice on treatment to patients with cancers. A review based on a symposium held at the 10th annual conference of the British Psychosocial Oncology Group, December 1993. *Eur J Cancer* 1995;31A:112-6.
- Deber RB. Physicians in health care management: 8. The patient-physician partnership: decision making, problem solving and the desire to participate. *Can Med Assoc J* 1994;151:423-7.
- Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA, Trichter DL, Till JE. Cancer patients: their desire for information and participation in treatment decisions. *J R Soc Med* 1989;82:260-3.
- Greenfield S, Kaplan S, Ware JE. Expanding patient involvement in care: effects on patient outcomes. *Ann Intern Med* 1985;102:520-8.
- Kaplan SH, Greenfield S, Ware JE. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Med Care* 1989;27(suppl):S110-27.
- Brody DS, Miller SM, Lerman CE, Smith DG, Caputo GC. Patient perception of involvement in medical care: relationship to illness attitudes and outcomes. *J Gen Intern Med* 1989;4:506-11.
- Llewellyn-Thomas HA, McGreal MJ, Thiel EC, Fine S, Erlichman C. Patients' willingness to enter clinical trials: measuring the association with perceived benefit and preference for decision participation. *Soc Sci Med* 1991;32:35-42.
- Parsons T. *The social system*. New York: Free Press; 1951.
- Brody DS. The patient's role in clinical decision making. *Ann Intern Med* 1980;93:718-22.
- Jones TV, Gerrity MS, Earp J. Written case simulations: Do they predict physicians' behavior? *J Clin Epidemiol* 1990;43:805-15.
- Kaplan SH, Gandek B, Greenfield S, Rogers W, Ware JE. Patient and visit characteristics related to physicians' participatory decision-making style. Results from the Medical Outcomes Study. *Med Care* 1995;33:1176-87.
- Laine C, Davidoff F. Patient-centered medicine. A professional evolution. *JAMA* 1996;275:152-6.

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### Appendix 1: Vignettes on diseases and treatment options used in the questionnaire

- In the last 2 weeks you have been bothered by scaly, itchy skin between the toes. The spots are spreading gradually. Your family physician examines your feet and diagnoses athlete's foot. It is not a serious disorder but rather a bothersome one, which will not disappear spontaneously. Two remedies are available, both in the form of an ointment. Ointment A is known to cure most cases of athlete's foot within a week. There is, however, a very small chance of an allergic reaction to the ointment, including symptoms such as a rash, fever and serious itching all over the body that need to be controlled by medication. The alternative treatment is ointment B. It does not cause any allergic reactions, but the chances of the athlete's foot disappearing within a week are smaller.
- For some time you have known that you have gallstones, but you have no symptoms. The surgeon tells you that there are 2 treatment options. The first is to wait and see. Experience shows that many patients with gallstones never have any symptoms, but a small percentage do. If there are symptoms they usually take the form of biliary colic, and emergency surgery is needed. For every surgical procedure, including this one, there is a chance of complications. The alternative is surgery while you are still free of symptoms. The surgery involves removing the gallbladder. This type of surgery has a lower risk of complications than the emergency surgery.
- Assume you receive a diagnosis of cancer of the larynx. The doctor tells you that in your case 2 treatment options exist. The first is surgery, which involves removal of the larynx, including the tumour. Because this procedure removes the vocal cords as well, this means that you would lose your voice. At the bottom of your neck an opening (tracheostomy) would be made in your windpipe. From then on, breathing in and out would take place through this opening, not through your nose and mouth. In principle you could learn to speak through your esophagus, or a voice prosthesis could be implanted, but your voice would never be as it was before. The other treatment is radiotherapy. The advantage of this type of treatment is that you would not lose your voice. However, your voice might be less clear as a result of the radiotherapy. Radiotherapy takes place in the hospital, 4 or 5 times a week for 5 weeks. You would not have to be admitted to hospital. Assume that the chances of cure are higher for surgery than for radiotherapy.
- Assume that skin cancer has been diagnosed. The tumour is on your back, just below the shoulder blade. Although it is malignant, the chances of cure are very high. The doctor tells you that 2 options exist. One is a small operation under local anesthetic in which the tumour is cut away. The other is a new form of treatment in which the tumour is frozen and dies off. In both cases the intervention is simple, but both carry a risk of complications such as temporary problems with wound healing and persisting problems with moving the shoulder. The risk related to the surgery is greater, but the chance of cure with this treatment is also greater.